



Coordinamento Toscano delle Associazioni per la Salute Mentale
Via Simonetti, 32 – 55100 S.Vito Lucca – Tel/Fax 0583-440615
www.coordinamentotoscanosalutementale.it

Coordinamento Toscano delle Associazioni per la Salute Mentale
Presentation

28 - 29 June 2017

Lunbeck - Global Patient Advocacy Summit
One voice – Together we will make a difference

Chiara Piletti

Coordinamento Toscano delle Associazioni
per la Salute Mentale



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Attendees to this summit

- **Chiara Piletti – Coordinamento and F.A.S.M. volunteer**
- **Lucia Piletti – Coordinamento and F.A.S.M. patient**
- **Serena Berti – Coordinamento Volunteer and F.A.S.M. volunteer of Italian civil service**



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Coordinamento Toscano delle Associazioni per la Salute Mentale was born on April 29th, 1993 and at the moment 50 associations of families and patients, based on all the Tuscan Provinces, are part of it.



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Coordinamento main purposes are

- **to defend the rights of people with mental diseases and of their families, being a spokesman with Tuscan Region with which there is a collaborative dialogue ever since;**
- **to fight the stigma against people who suffer of mental diseases;**
- **to improve the services and the social, working and accomodation integration for these people and their families.**



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Coordinamento organizes

- **conventions of verification on the law application upon our Region;**
- **events to inform, understand and guide positively people regarding mental health themes;**
- **periodic meetings with the Regional Institutions;**
- **periodic meetings (every 2 months) with all the associations belonging to it.**

Coordinamento joins

- **Regional and National working Tables.**



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Coordinamento

- **is CESVOT (Tuscan Services Center for Volunteering) Partner**
- **joins *Piattaforma Nazionale per La Salute Mentale* belonging to *Mental Health Europe (MHE)* regarding PROGRESS project.** In particular, the project is aimed to realize, create and develop in each European Country a National Platform for Mental Health which unifies the main organisations of this sector, starting from patient associations where they are present or they are going to be created.
- **joins *Coordinamento Di Poi Durante e dopo di noi* (to ask for services which can ensure a safe and peaceful future when relatives are no longer alive for people with mental deficiencies).**
- **joins CNV (Volunteering National Center)**



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Carta per la Salute Mentale

April 12th 2017

Italian Republic Senate



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On april 12th, 2017 *Carta per la Salute Mentale* has been presented at the Italian Republic Senate.

This initiative has been promoted by SIP (Italian Psychiatric Society) in collaboration with Fondazione Progetto Itaca onlus, Fondazione Internazionale Don Luigi Di Liegro onlus, Coordinamento Toscano delle Associazioni per la Salute Mentale and SIFO (Hospital Pharmacy Italian Society).

This document contains a list of priorities in order to make the Institutions understand which is the current status of Italian Mental Health aids and services and start a productive and pragmatic dialogue.



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Coordinamento

- is very satisfied as all the requests that have been done to Institutions and to services in the last 20 years have been completely listed in this document;
- is pleased that in this occasion ***Scientific Societies and Families/Patients Associations worked together*** with a unique purpose which is the wellness promotion of people with mental discomforts.



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Carta della Salute Mentale



Gemma Del Carlo

Coordinamento's President
12 April 2017 - Italian Republic Senate



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The creation of this document has been encouraged also by 2 OMS Resolution and Action Plan for Mental Health 2013-2020 where all the Member States are invited to adopt them and to activate programs for

- mental health promotion and prevention,**
- care treatments,**
- allocation of enough funds to this aim.**



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We hope that **Carta per la Salute Mentale** will be an additional recall to Italian Health Ministry in order to verify if laws regarding mental health are or not applied.

Families and patients completely agree with Mental Health Tuscan Region and Italian Regulations, but these regulations are not always applied as they should.



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Coordinamento says thanks to **Pisa University** which invite it to cooperate starting from a first seminary held at **CNR (National Research Italian Center)** (November, 8th 2016).

In the role diversity there is a common aim which is the wellness of **people with mental discomforts.**



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There is a collaborative dialogue with Tuscan Region started 12 years ago with the current President Enrico Rossi, thanks to the contribution of all the Associations and to the reciprocal estimation; this important collaboration is proceeding with the current Assessors for

- Health and Social politics (Stefania Saccardi)**
- Others (i.e. job)**

They all appreciate our work and they encourage us to go on in this way.



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There is an interesting protocol between Region and Coordinamento, that has been renewed on August, 1st 2016 which formalizes the reciprocal cooperation that exists among them.

With this protocol the two entities commit themselves to plan joined actions and to cooperate with shared programs.



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**Tuscan Region identifies in our work a
proactive and supervising role
which lets Coordinamento be present
to Institutional working meetings.**



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The most important event that is yearly organized by Coordinamento together with Tuscan Region is a Convention held in Florence with the title:

How much patient is involved centrally in his care. 12° Convention of planning and validation regarding the operation of integrated mental health services.

Every year we record more than 300 participants.



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Conventions organized by
Coordinamento Toscano and Regione Toscana

How much patient is involved centrally in his care. Convention of planning and validation regarding the operation of integrated mental health services



2005 - 2016

15th November 2005
27th November 2006
23th November 2007
28th November 2008
1st December 2009
29th November 2010
29th November 2011
29th November 2012
29th November 2013
28th November 2014
3rd December 2015
16th November 2016

Firenze – Auditorium Gruppo MPS



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These conventions main purpose is to verify yearly Mental Health Services status supplied by Tuscan Sanitary Companies and to propose action to improve the current situation, in respect with the current laws, which all the association agree with, but they are not applied completely on all the territories.



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In this yearly conventions
Associations, Health Care Directors,
Regional and National Institutional
Representatives, Professionals and
***University Representatives* describe the**
situation with their point of view,
discuss together and start planning
improvement actions where needed.



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Convention organized by
Coordinamento Toscano and Regione Toscana
16th November 2016



Gemma Del Carlo
Coordinamento's President



Stefania Saccardi
Health and Social Politics Assessor



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Convention organized by
Coordinamento Toscano and Regione Toscana
16th November 2016



Teresa Di Flandra
Italian Health Ministry
Prevention General Direction
Vulnerable People Advocacy



Andrea Fagiolini
Psychiatric Clinic Director and Psychiatric
Specialization School at Siena University
Area Vasta Sud Est Tuscan Mental Health Director



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Convention organized by
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16th November 2016



Health Tuscan Companies Directors



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Convention organized by
Coordinamento Toscano and Regione Toscana
16th November 2016



Coordinamento's Volunteer's
at the Convention Reception



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Mental Health provided data are not satisfying.

In particular the expense for mental health is not enough: nor the Tuscan Region rule of 4,5% is respected, neither the National one which is of 5% !!!



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We state the importance of having a unique planning informatic system in Tuscany with a flow of all the events and a informatic clinic record with all the patient history and that lets the professionals evaluate the efficiency of all the performed actions.

Besides it would facilitate the communication with the basic doctor and with the pediatrician.

It's also mandatory to have the flows related to the social assistance.



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The most serious critical issue reported by Coordinamento is related to childhood.

It's important to act in advance on the discomforts and to look after in advance to avoid future complications.

The role of pediatrician and of the basic doctor is very important and they need an accurate education.



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Another critical issue is the taking care of people with **mental insufficiency where there is a complete skill rebound among health cares and social services.**



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Coordinamento cooperates with Mental Health services and have confidence in General Health Tuscan Directors, as a good dialogue exists with them in a mutual estimation relation-ship, but it is also convinced to make the laws be respected, in order to **have the personalized and individual care path be completely applied.**

By improving quality services we obtain also an important cost saving, and, most of all a lot of **wellness for the patient.**



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Discomforts caused by Autism



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People with autism are increasing and Regional Health Office solicits a bigger attention.

Tuscan Region financed sperimental projects for autism with good and satisfying results.

We ask to give continuity and not to stop these interesting projects; otherwise this investment will be only a waste of money.



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**Issues have been reported
regarding boys and girls that
leave childhood health services
and are then taken in charge by
adults health services as
continuity is not found in
rehabilitative projects.**



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Difficult relations are reported, in many realities, between Mental Services Departments and drugs addiction Services, particularly regarding the management of patients in deep crisis, double diagnosis and pathological games dependencies. Professionals of the two services do not communicate enough with deep difficulties for patients and relatives. In some areas protocols have been produced to integrate the 2 services, but they are not working fine.



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**There is also an increase of
teenagers that make use of
alcoholic drinks and drugs.**

This is really worrying.



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Many people are reporting issues regarding support administrator, because instead of helping the person to recover his autonomy, sometimes he becomes a substitute of a tutor and other times he follows just the economic aspect.

Law states that the person to be chosen has to be close to the family and from the reportings this not often happens.



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Personalized and Individual Project



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From mental disorder it's possibile to heal or at least stay better.

We know that the answer to mental issues is

- **in the integration of health and social services realized in advance and coordinated in the same time and**
- **in the activation of Health Integration Plans, starting from Personalized and Individual Project and from an accurate actions evaluation.**



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Personalized and Individual Project

- **is a detection of needs**
- **defines who is in charge of the needed actions**
- **consider social and health action as needed, shared with the patient and his family, focus on his care, his rehabilitation, social, housing and working integration.**



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**In the care and life project it's
necessary to let the person be
everyday more independent also
thanks to his *job, which is a right for
everyone.***



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Mental Health staff needs to be stable and replaced before the retirements, pregnancies and for authorization of leave for 104 and 1204 laws (invalid relatives).

Staff stability is fundamental as it lets the professionals create a empathic relationship with the the patient and his family in order to enhance and develop his potentiality, increasing his self confidence.



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Operator needs to be educated and qualified so that he can encourage the person to be more self confident, and instruct him to take care of himself and to respect the others in order to receive more easily respect from the other ones.



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Family needs to be hold, instructed, apprised, supported by the services and routed to associations and to self help groups where, through the share, problems are better beared.

We have always asked to have the project be written and shared with the family.



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Pharmacological therapy is necessary, but without any other actions it cannot be enough.

Fondamentals are instead social-recovery actions i.e. art and music therapy laboratories, theatre acting courses, sports etc. If these are missed chronicity is helped. Unlinkely places where to perform these activities are often not available.



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The personalized project, besides detecting the needs and defining who has the responsibility of the patient care, avoids also to have duplicated and not coordinated activities on the patient.

In addition this could be an interesting instrument to highlight other issues regarding phisical health, where there is lacking and insufficient attention.



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Association Roles



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In the personalized project, remarkable importance (now more than ever as we are in a crisis economic period) come from the associations with

- **their listening and self-help services,**
- **the experiences of social facilitators,**
- **their ludic-leisure, sport and cultural activities in the spare time.**

All these initiatives foster socialization, integration in the territory and the involvement of citizens.



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The active and collaborative role of the patient and family importance is reaffirmed also in the declaration of European Regional Office of OMS 2010 “The Empowerment of patient in Mental Health”.

This strengthens our belief that it's also necessary to adopt measurement instruments for the evaluation of the families psychological and social sufferings.



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Besides, the document reports the frequent paternalistic and negative behavior of Mental Health professionals: sometimes they suppose in fact that patients and their families are not able to take decisions; this restricts quality and the number of decisions that they can take leading to long term dependency.



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National Level Requests



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- **Change of the situation related to yearly income for people with disability less than 99%.**
- **Change of 68/99 law for the part concerning the possibility for the companies to pay a penalty instead of hiring invalid staff.**
- **We think it's really bad that a company can choose the disability type for hiring.**



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It has been a lot of years that we are stating the need of increasing yearly income from the current € 4.738,00 to at least € 8.000,00, as for unemployed people.

For people with disability less than 100% and with € 275,00 monthly well payment, a part-time job would be therapeutic and would be an integration, letting them becoming more indipendent; unfortunately at the moment with a part-time job the welfare payment is lost and people does not accept the job.

For people with 100% disability, the income is € 14.256,92



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Driving Licence Renewal

We ask

- **to abrogate the tax for yearly controls and pay it every 10 years as stated for all the citizens.**
- **to have a psychiatrist of the public service in the medical commission for people who make use of psychiatric medicines.**



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We finally invite Regions and Local entities to integrate services as the law state and we restate the importance of planning and validating the actions.

Patients and families need to commit themselves to find their active role and at the same time involve citizens in the social intergration because

EVERY SUBJECT WITH HIS ROLE
CANNOT SUBSTITUTE THE OTHER